

Perspective

Case-finding in clinical practice: An appropriate strategy for dementia identification?

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Abstract

Earlier diagnosis of dementia is increasingly being recognized as a public health priority. As screening is not generally recommended, case-finding in clinical practice is encouraged as an alternative dementia identification strategy. The approaches of screening and case-finding are often confused, with uncertainty about what case-finding should involve and under what circumstances it is appropriate. We propose a formal definition of dementia case-finding with a clear distinction from screening. We critically examine case-finding policy and practice and propose evidence requirements for implementation in clinical practice. Finally, we present a case-finding pathway and discuss the available evidence for best practice at each stage, with recommendations for research and practice. In conclusion, dementia case-finding is a promising strategy but currently not appropriate due to the substantial gaps in the evidence base for several components of this approach.

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Keywords:

Case-finding; Screening; Dementia; Early identification; Diagnosis; Clinical practice; Policy

1. Background

1.1. The case for early diagnosis

Balancing the potential harms and benefits of diagnosing dementia is a contentious issue as there are no disease-modifying treatments for dementia, and a formal diagnosis may not benefit everyone [1]. A recent systematic review found that most people both with and without cognitive impairment, would prefer to know if they had dementia to allow greater autonomy in decision-making for future care and legal issues and time to prepare for challenges [2]. These perceived benefits are contingent on receipt of a timely diagnosis, allowing earlier access to resources and services such as symptom management and psychosocial interventions. A missed or delayed diagnosis limits these opportunities and can compromise safety [3]. Economic modeling also suggests that earlier diagnosis is likely to be cost effective by increasing quality of life and delaying institutionalization

[4]. Earlier identification of dementia is an international health priority [5,6] and an important element of various National Dementia Strategies [7].

1.2. Challenges of identifying dementia

Many people with dementia never receive a diagnosis, and most cases in lower income countries are likely to be undiagnosed [5]. Dementia is challenging to diagnose, particularly in the early stages. Many symptoms overlap with conditions such as depression, delirium, and functional problems, and patients with dementia often do not report subjective cognitive complaints to a physician [8]. There is currently no single, accurate test to identify dementia, and family physicians' judgments of dementia status are often inaccurate [9]. Barriers to the diagnosis of dementia commonly identified by physicians include lack of knowledge and confidence, inadequate tools and protocols, concerns regarding potential harms of diagnosis, risk of misclassification, and difficulty of communicating a diagnosis [10]. Population screening for dementia is currently

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Box 1 Examples of screening and case-finding definitions

Definition of Screening

- “A public health service in which members of a defined population, who do not necessarily perceive they are at risk of, or are already affected by, a disease or its complications, are asked a question or offered a test to identify those individuals who are more likely to be helped than harmed by further tests or treatment to reduce the risk of disease or its complications” [16].

Descriptions of case-finding

- “That form of screening of which the main objective is to detect disease and bring patients to treatment, in contrast to epidemiological surveys” [17].
- “A systematic or opportunistic process that identifies individuals (e.g., people with COPD) from a larger population for a specific purpose, for example, Flu vaccination” [18].

Description of case-finding used within the context of dementia identification:

- “Identification of possible/probable dementia... targeted on those with a higher prior probability of having the disease” [14].
- “Assessment of a subgroup of individuals identified on the basis of known risk factors (e.g., subjective cognitive concerns or family history of dementia) to be carried out by physicians and other health professionals” [15].
- “Case-finding is aimed at individual patients who in the clinical opinion of the GP may benefit from a dementia assessment” [19].

not recommended by evidence scrutiny bodies for national screening programs in the UK and United States due to insufficient evidence of the potential benefits and harms [11,12]. Instead, clinical guidelines recommend case-finding in clinical practice, where clinicians offer a dementia investigation to patients attending consultations for other reasons [13–15].

In this review, we examine the concept of case-finding and how it differs from screening. We provide a formal definition of dementia case-finding and consider under what conditions it is appropriate. Finally, we outline a dementia case-finding pathway and the evidence for best practice at each stage.

2. What is dementia case-finding? A conceptual framework

Missing from the literature is an agreed definition of “case-finding”. There is much ambiguity around what it means, particularly with respect to how it differs from screening (see Box 1). An editorial by Wald and Morris [20] called for the term “case-finding” to be abandoned due to concern that the term may be used to justify a screening initiative while avoiding the need for an evidenced, evaluated program with a demonstrated benefit. The dementia identification strategies of screening and case-finding continue to be confused, with direct impact on patients and clinicians due to the lack of evidence accompanying implementation, and McCartney has noted the need for a formal definition of case-finding [21].

2.1. A formal definition of dementia case-finding

To improve the clarity of what dementia case-finding is and under what conditions it may be appropriate, we propose the following definition:

“An offer of a brief, opportunistic investigation to identify possible signs or symptoms of dementia, initiated by a clinician during consultation with a patient at high risk of dementia on the basis of clinical judgment that an initial dementia enquiry is appropriate and is likely to benefit the patient”.

This definition encompasses the following four features:

Purpose: To identify a possible case of unrecognized dementia for potential benefit to the patient.

Context: The decision to offer dementia case-finding is made during a clinical consultation with a patient, where the clinician has no preexisting concern of possible signs of dementia, and the patient has not raised any self-reported cognitive complaints. Unlike a screening program, the decision to offer case-finding relies on a patient-centered clinical judgment of appropriateness and potential benefit for a given patient.

Target group: A patient offered case-finding should meet predefined criteria for membership in an evidence-based high-risk group.

Process: Case-finding is offered and not imposed on the patient. The patient should give prior consent to any case-finding investigations or tests. The definition intentionally excludes the method of investigation, which should be chosen in accordance with the best evidence and guidance available at the time. The process of case-finding is not synonymous with a brief cognitive assessment, although this may form part of the case-finding process. Identification of a concern at this stage would warrant further investigation or referral to specialist services.

Adoption of this definition of dementia case-finding would have implications for patients, clinicians, health-care providers and systems, and political bodies. The term would no longer serve as a vague description to justify

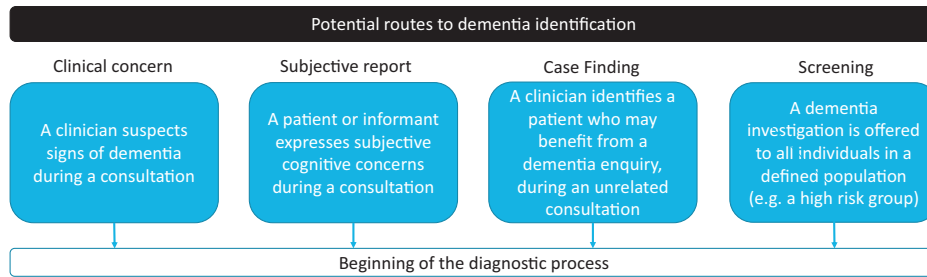


Fig. 1. Potential routes to the identification of dementia.

dementia screening interventions. Instead, it would require an evidence-based protocol for the identification of patients for whom the offer of case-finding is appropriate. This protects patients from potentially inappropriate or ill-advised policies and procedures, supports clinical decision-making, and provides a clear basis for the development and assessment of evidence-based practice.

2.2. Differentiating the routes to the identification of dementia

Case-finding is one of four potential routes to a dementia diagnosis (see Fig. 1). These are as follows: (a) clinical recognition of signs or symptoms, (b) investigation of subjective concerns (reported by the patient or an informant), (c) case-finding in clinical practice, and (d) population screening. The World Health Organization [14] notes the importance of distinguishing between dementia case-finding and screening. They emphasize that the difference is that case-finding is conducted by targeting high-risk groups. However, all population-screening programs are restricted to specific groups, for example, stratifying by age. Risk stratification therefore does not distinguish between screening and case-finding. Indeed, the UK National Screening Committee (NSC) [16] highlights the importance of allowing screening programs to target high-risk groups.

Other efforts to distinguish between these related approaches have emphasized that case-finding is conducted opportunistically with patients who have initiated contact with the clinician by attending for another reason. In contrast, if patients are invited to attend for screening, this carries an implied benefit of that screening [22,23]. However, this does not provide a sufficient distinction, as screening practices may be conducted opportunistically, for example, screening for hypertension by checking blood pressure during outpatient visits [24]. Moreover, we agree with the position taken by Wald and Morris [25]; the fact that the investigation is conducted opportunistically when the patient has attended for an unrelated matter should not impinge on the requirement for evidenced potential benefit.

Our distinction between screening and case-finding is focused on the clinical context itself; screening programs specify the offer of investigation to all individuals in a predefined group. In contrast, case-finding involves

patient-centered clinical judgment to assess whether offering the investigation is appropriate and of potential benefit in the case of a specific patient. The ethical implication of clinical decision-making in the initiation of case-finding is a subtle but crucial difference between the related approaches of screening and case-finding. This is of core clinical importance with implications for both patients and clinicians. In Table 1, we provide a more detailed comparison according to our proposed definition of dementia case-finding.

3. Dementia identification policy and practice

To illustrate the subtle but important difference between case-finding and screening in clinical practice, we review two recent examples of government initiatives to improve the identification of dementia.

3.1. Case study 1: United States—detection of cognitive impairment in the Annual Wellness Visit

Medicare is a federal health insurance program for US residents aged 65 and older, in addition to certain younger people with disabilities and people with end-stage renal disease. Since 2011, the Affordable Care Act has required the provision of a Medicare Annual Wellness Visit to detect any cognitive impairment, including dementia. This involves an assessment of cognitive function by physician observation and interview with the patient and a knowledgeable informant about subjective cognitive impairment [26]. To operationalize the detection of cognitive impairment during the Annual Wellness Visit, an expert workgroup, convened by the Alzheimer's Association, produced the "Medicare Annual Wellness Visit algorithm for assessment of cognition" which recommends a referral or full dementia evaluation for potential cases [27]. The algorithm recommends a structured cognitive assessment if the clinician, patient, or informant report possible signs or symptoms of dementia. It also recommends an assessment if there is no informant available, even if no concerns are held by the patient or the clinician.

There is a lack of evidence for the impact or acceptability of this approach, and the take-up by eligible beneficiaries has been low. In 2014, the visit was received by less than 16% of all eligible beneficiaries, with regional rates ranging from 3% to

Table 1
Comparison of screening and case-finding dementia identification strategies

| Strategy characteristics | Screening | Case-finding |
|---------------------------------|--|--|
| Process | An initial investigation such as a question or simple test, with a positive indication followed by an offer of further investigation. | Identical to screening. |
| Type of initiative | May be systematic (e.g., target patients are invited to attend a screening appointment) or opportunistic (e.g., an offer of a test when patients attend a consultation). | Opportunistic and based on clinical judgment of potential benefit during a consultation. |
| Scale of initiative | Invitations for screening may be large scale (e.g., national programs) or small scale (e.g., specific health trusts with low diagnostic rates or diseases in certain geographical areas). | Forms part of clinical practice, although clinicians may be encouraged to conduct case-finding by national or regional policy in response to low diagnostic rates. |
| Target groups | May be targeted on a broad population (e.g., women aged 25–60) or more narrowly defined high-risk groups (e.g., those with specific medical conditions). An important element is that it is offered to nonsymptomatic individuals. | Targeted on selected high-risk groups on a case-by-case basis according to the clinician's judgment of potential benefit. |
| Evidence requirements | Formal assessment of a screening program proposal against criteria regarding knowledge of the condition and potential benefits and harms of screening to the target group as a whole. | No formal evidence requirements at present. |
| Who initiates the investigation | The body responsible for screening program implementation. | The clinician, in making a decision that it may benefit a specific patient. |

34% [28]. Using our conceptual framework, we would define this initiative as an example of screening rather than case-finding, as it assumes broad suitability without patient-centered clinical judgment of potential benefit from the assessment.

3.2. Case study 2: England—*incentivized detection of dementia in the National Health Service*

The Department of Health is responsible for policy and funding of health and care in England. In recent years, it introduced two separate financial incentive schemes, encouraging clinicians to identify dementia during routine clinical practice in primary care [29] and hospital settings [30]. Different “at-risk” criteria were defined for each setting (Box 2), although clinicians were required to ask the same question to identify subjective cognitive concern;

“Have you/has [the patient] been more forgetful in the past 12 months, to the extent that it has significantly affected your/their daily life? (Ask patient/relative/carer)”.

In the absence of an informant, further investigation was not recommended if the patient responded negatively. Therefore, this relies more heavily on the patient's subjective report than in the Annual Wellness Visit. The classification accuracy of this approach is unknown, but use of subjective memory complaints has been highlighted as inappropriate for dementia case-finding [8]. Both the risk-group criteria and the subjective cognition question were developed by clinical consensus, and neither has been validated empirically. In addition, there is no alternative question provided for use with people with learning difficulties despite learning difficulty being a risk factor.

The primary care scheme specification stated that the initial dementia enquiry was to be conducted only if the clinician believed it to be clinically appropriate and of potential benefit to the patient. In contrast to the Annual Wellness Visit, we regard this to be an example of case-finding, as it requires a patient-centered evaluation of whether a dementia investigation may be appropriate for a particular individual. The incentives were based solely on the proportion of high-risk patients

Box 2 Department of Health “at-risk” criteria for dementia

Risk criteria for use in primary care [29].

- Aged 60 years or older with cardiovascular disease, stroke, peripheral vascular disease, or diabetes
- Aged more than 60 years and have a “high risk” of cardiovascular disease, for instance because of smoking, alcohol consumption, or obesity
- Aged more than 60 years with a COPD diagnosis
- Aged 40 years or older with Down's syndrome
- Aged 50 years or older with learning disabilities
- Long-term neurological conditions that have a known neurodegenerative element, for example, Parkinson's disease. Risk criteria for use in hospitals [30].
- Over 75s who are the subject of an emergency admission to hospital or community services and are not already diagnosed with dementia.

Table 2
Suggested dementia case-finding evidence requirements

| Proposed criteria | Currently met? |
|---|---|
| The condition | |
| 1. The condition should be an important health problem. | Yes |
| 2. The epidemiology and natural history of the condition, including development from latent to declared disease, should be adequately understood, and there should be a detectable risk factor, disease marker, latent period, or early symptomatic stage. | No |
| 3. All the cost-effective primary prevention interventions should have been implemented as far as practicable. | Difficult to assess |
| The test | |
| 4. There should be a simple, safe, precise, and validated case-finding test. The distribution of test values in the target population should be known and a suitable cutoff level defined and agreed. | Partially met, awaiting clarification of optimal cutoff levels. |
| 5. The test should be acceptable to the population. | No |
| 6. There should be an agreed policy on the further diagnostic investigation of individuals with a positive test result and on the choices available to those individuals. | Yes |
| The treatment | |
| 7. There should be an effective treatment or intervention for patients identified through early detection, with evidence of early treatment leading to better outcomes than late treatment. | No |
| 8. There should be agreed evidence-based policies covering which individuals should be offered treatment and the appropriate treatment to be offered. | Yes |
| 9. Clinical management of the condition and patient outcomes should be optimized in all health-care providers before participation in a case-finding program. | Not possible to assess |
| The case-finding program | |
| 10. There should be evidence from high-quality randomized controlled trials that the case-finding program is effective in reducing mortality or morbidity. | No |
| 11. There should be evidence that the complete case-finding program (test, diagnostic procedures, and treatment/intervention) is clinically, socially, and ethically acceptable to health professionals and the public. | No |
| 12. The benefit from the case-finding program should outweigh the physical and psychological harm (caused by the test, diagnostic procedures, and treatment). | No |
| 13. All other options for managing the condition should have been considered (e.g., improving treatment, providing other services), to ensure that no more cost-effective intervention could be introduced or current interventions increased within the resources available. | No |
| 14. There should be evidence that clinicians can assess the potential benefits of case-finding. | No |

to whom case-finding was applied, and as such, the scheme received much criticism. Concerns were raised regarding the lack of evidence and harms of false positives, including impact on patients and overload on memory services, with suspicion that this was a dementia screening initiative being implemented under the guise of case-finding in the absence of evidence [21,31–33]. The scheme was dropped in 2016.

A separate scheme for hospital settings in England was also introduced as a “case-finding” strategy, although we suggest this is better described as an example of screening. It was applied to all unplanned (emergency) admissions of inpatients aged 75 years and older, with no further consideration of potential benefit to individual patients. Affirmative responses to the subjective cognition question were followed by the Abbreviated Mental Test Score. This practice has since become a mandatory component in the standard General Medical Services contract [34], and the CAsE finding in hospitals - impacts on CAre for people with DEmentia (CASCADe) study [35] is currently investigating the effectiveness of this policy and its impact on patients. Taken together, these examples demonstrate the subtle but important differences in the approaches to dementia identification in policy and clinical practice.

4. Is case-finding currently appropriate for dementia identification?

Case-finding for dementia offers the potential to identify more people for whom a diagnosis may otherwise be missed or delayed. However, we must be cautious to ensure that the potential risk of harm both from false negative and positive diagnoses is minimized. There are currently no existing evidence requirements against which case-finding initiatives are assessed, and harm may be caused by inappropriate or ineffective case-finding strategies. Therefore, we reviewed the criteria for assessing evidence for screening proposals and suggest that they also apply to case-finding. We used the UK NSC criteria, which provide broad coverage of the various screening criteria items used internationally to make recommendations regarding population screening proposals [36]. The NSC is also one of only two bodies that require knowledge of the distribution of test values in the target population, with agreed cutoff levels. This is particularly relevant to the assessment of cognition.

Table 2 shows our proposed case-finding evidence criteria, and whether each criterion is currently met. This is based on the most recent appraisal against the NSC criteria, with an

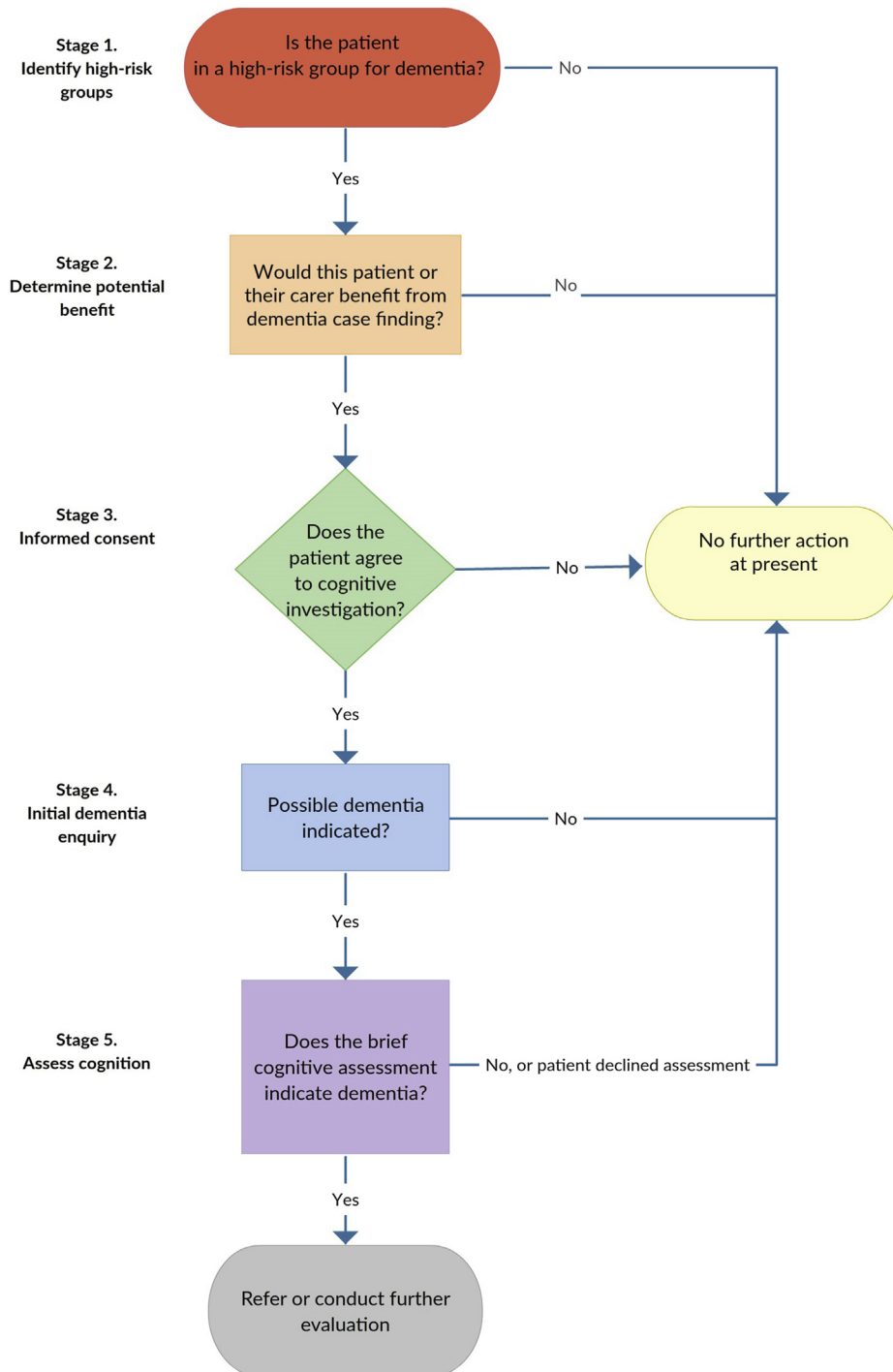


Fig. 2. Dementia case-finding pathway.

additional criterion of evidence for clinical judgment of potential benefit to a given patient. We suggest that case-finding, as defined in this review, is a promising dementia identification strategy and would be appropriate under these conditions. However, according to the available evidence, not all of these criteria are currently met. A recent systematic review found that dementia screening may not be acceptable to either

patients or clinicians [37]. Several of the barriers to acceptance related to the clinical context (role of the clinician, clinical communication, benefit, and the patient's existing health, lifestyle, and comorbidities). We therefore suggest that case-finding may be more acceptable than screening, due to the role of clinical judgment in offering case-finding, with patient-focused consideration of potential benefit.

5. What would appropriate dementia case-finding look like?

There is no agreed best practice for dementia case-finding, and there is inconsistency in clinical guideline recommendations for the initial identification of possible cases. The dementia case-finding pathway in Fig. 2 illustrates the five stages in the case-finding process that require consideration. We review the quality of evidence for each stage in the process and recommend further research to address the evidence gaps. This could support the development of an evidence-based case-finding protocol for dementia.

5.1. Stage one: Identify high-risk groups

To which individuals should case-finding be offered? Various high-risk groups have been proposed, for which the evidence base is unclear [15,29,34]. We suggest the use of population-based cohort studies to inform the development of clinical guidelines, by identifying patient groups and combinations of patient characteristics which are strongly and consistently associated with dementia.

5.2. Stage two: Determine which patients are likely to benefit from case-finding

There is a lack of literature on how clinicians can effectively determine whether a given patient may benefit from dementia enquiry. What comprises benefit for a patient? Established screening criteria focuses on reducing mortality and morbidity, although in the case of dementia, this needs to incorporate improvement in quality of life in addition to symptom management. For example, Olde Rikkert et al. [38] suggest assessing cognition only in patients who report a decline in well-being, on the basis that these individuals are likely to have the greatest scope for improvement. There is currently no evidence to suggest whether this approach would be effective or acceptable to patients and clinicians.

It is important to note that potential benefits, such as improved management and treatment resulting from case-finding, also extend beyond the patient; families and carers may benefit from support services where they are available, and health service providers and payers may benefit economically from reduction in avoidable crises and admissions, particularly in areas where undiagnosed dementia is a priority. Further work in this area should focus on identifying which patient characteristics, case-finding strategies, and clinical contexts are associated with enhanced patient outcomes to support clinical decision-making.

5.3. Stage three: Obtain informed consent for cognitive investigation

Screening-appraisal bodies emphasize that patients should decide whether to engage in screening according to the risks and benefits to them as an individual. This ethical framework

should apply equally to case-finding, allowing patients to make an informed choice of whether to accept an offer of case-finding. Agreement should therefore be established from the very beginning of any case-finding process, and there is a need for an agreed procedure to facilitate access to case-finding that is acceptable to both patients and clinicians.

5.4. Stage four: Initial dementia enquiry

A single question used to identify those most likely to have dementia would have the advantage of avoiding unnecessary cognitive assessment. However, despite the tempting brevity of single-item case-finding questions, their usage is inappropriate unless validated in the relevant population and clinical setting, are acceptable to patients and clinicians, and offer a reasonable balance of sensitivity and specificity for a particular clinical context. Questions measuring subjective cognition are particularly problematic; despite subjective cognitive complaints being associated with dementia [39], they are common in older people both with and without objective cognitive deficits, and most people with dementia do not report memory problems when asked [40]. The proportion of cases missed by this approach is high [8], so the use of a patient-reported subjective cognition question is not currently suitable for case-finding for dementia in a clinical setting.

Little research has evaluated case-finding questions for dementia. Lessons may be learned from better-studied areas of psychiatric case-finding. For example, incorporating an additional question depending on the patient's responses has shown to be successful in diagnostic accuracy studies for case-finding questions used in depression [41]. This approach has been found to be acceptable to patients [42]. In contrast, informant-reported subjective cognition may be a more reliable indication of dementia status. In a nationally representative population-based study, an informant-reported single question adequately discriminated between older adults with and without dementia, outperforming the overall accuracy of the Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE), a validated informant questionnaire [43]. A recent test-accuracy pilot study assessing the diagnostic properties of an informant-rated single-item case-finding question for use in hospital settings also indicates that this approach may be suitable for dementia case-finding [44]. This used a five-point Likert scale response to the question "How has your relative/friend's memory changed over the past 5 years (up to just before their current illness)?" Any deterioration indicated cognitive impairment, and this question performed well compared with the IQCODE. An informant-reported single question such as this may be useful, before the offer of cognitive assessment, to identify individuals for whom a cognitive assessment is suitable while reducing unnecessary testing.

These findings are encouraging, but the evidence is not currently sufficient to enable recommendation of a single question to form part of dementia case-finding. Validation

of an informant-rated single question in the relevant clinical settings against a formal dementia diagnosis is required.

5.5. Stage five: Conduct a brief cognitive assessment

A recent systematic review of dementia practice guidelines found general agreement on the recommendation of using standardized brief cognitive assessment although there was variation in the specific tools recommended, including Mini-Mental State Examination, General Practitioner Assessment of Cognition, and the Montreal Cognitive Assessment amongst several others [45]. Identification of the most appropriate cognitive assessment depends on the setting in which it will be used, for example, in primary or secondary care.

Some brief cognitive assessments are validated in the target clinical settings; though it should be noted that using a cognitive assessment in combination with a subjective cognition question requires revalidation of the procedure as a whole, and within the intended high-risk patient groups. Patient groups and context of usage may affect the diagnostic accuracy of the assessment. For example, if the assessment is conducted only following a report of subjective cognitive complaint, then the assessment is required to not only identify dementia cases from non-cases but also specifically distinguish dementia from other sources of cognitive complaints or concerns. The outcome of this stage would be further investigation, reassurance, or a scheduled follow-up.

6. Conclusions

The distinction between screening and case-finding is subtle but important, with direct relevance to patients and clinicians. Our definition of case-finding differentiates this practice from screening. Case-finding initiatives should be individualized, patient-focused, and subject to evidence requirements. Evidence-based case-finding is a promising strategy to improve diagnostic rates and increase the detection of cases. However, we do not currently recommend the implementation of dementia case-finding in clinical practice because the proposed evidence requirements for this are not yet met. We have identified the gaps in the evidence at each stage of the case-finding process, and specific areas requiring further research to inform evidence-based practice. They include criteria for targeting high-risk groups, identification of those likely to benefit from case-finding, and validation of an effective, acceptable dementia case-finding question or initial enquiry.

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RESEARCH IN CONTEXT

1. Systematic review: We reviewed the literature of case-finding in clinical practice as a strategy for the identification of dementia.
2. Interpretation: We examine the ambiguous concept of case-finding and highlight the lack of evidence requirements for public health strategies introduced under this term. We propose a formal definition of dementia case-finding with suggested evidence requirements, and provide a case-finding pathway to guide policy and clinical practice. This has the potential to inform appropriate and evidence-based dementia identification strategies.
3. Future directions: Only when the proposed evidence requirements are met would dementia case-finding in clinical practice be recommended. Currently it remains unclear whether patients may benefit from case-finding, and whether clinicians can assess potential benefit. Identification of appropriate criteria for targeting high risk groups requires investigation of patient and clinical characteristics associated with dementia status in population-based cohorts.

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